

# Family Health Dataline

## IN THIS ISSUE:

- During 1992-94, cause of death among infants as determined by the MIMR Committee did not agree with the death certificate 16-21% of the time.
- Most infants who died of SIDS were found in the prone sleeping position and with loose blankets covering them; maternal smoking during pregnancy or after birth was associated with an increased risk of SIDS.
- While deaths due to anencephaly have decreased during 1979-94, deaths due to autosomal trisomies have increased.
- For 14% of infant deaths during 1992-94, the MIMR Committee could not determine a cause of death; committee members felt abuse or neglect may have contributed to death for over half of these infants.

In this issue of Dataline, we continue our review of information collected from the Alaska Maternal-Infant Mortality Review (MIMR). We present results of analysis of 121 infant deaths which occurred during 1992-94. For some sections we have also included background information providing analysis of data from death certificates of infants who died during 1979-92.

## MIMR Results

### Cause of death

#### *Findings*

As presented in the previous issue of Dataline<sup>1</sup>, we reviewed 121 infant deaths which occurred during 1992-94. Because deaths were non-randomly selected for review (for example, Alaska Natives were underrepresented for reasons stated in the previous Dataline), the causes of deaths among cases we reviewed does not necessarily reflect the causes of death statewide. The review committee determined a consensus cause of death for each infant following review of all available records. For the 121 infants whose records we reviewed, the most common consensus causes of death were prematurity (27%), congenital anomalies (25%), and sudden infant death syndrome (SIDS) (23%). Infection caused only 5% of deaths while for 14% of deaths the committee could not determine a cause.

We compared consensus and death certificate causes of death. Death certificates were completed by numerous persons including 17 different pathologists. Using consensus cause of death as the gold standard, the sensitivity and positive predictive value of death certificate cause of death varied considerably (Table 1). In particular, only 80% of deaths attributed to SIDS and 71% of deaths attributed to infections by the death certificate were judged by the committee to have resulted from these causes. Additionally, of deaths for which the committee could not determine a cause, the death certificate reported unknown only 29% of the time. The agreement between the consensus and death certificate causes of death did not improve over time: during 1992, 1993, and 1994, the death certificate and consensus cause of death did not agree on 16%, 16%, and 21% of occasions.

**Table 1.** The sensitivity and positive predictive value of death certificate cause of death using a review committee consensus cause of death as the gold standard; Alaska MIMR, 1992-94.

	<i>Death Certificate cause of death</i>					
	Prematurity	Congenital anomaly	SIDS	Infection	Other	Unknown
Sensitivity	91%	83%	100%	100%	100%	29%
Positive Predictive value	97%	89%	80%	71%	80%	83%

## Recommendations

Most state and national groups formulate policy based on health indicators derived from death certificate data. Use of data to drive health care policy has assumed a larger role today with increasing emphasis on decreasing the cost of medical care. Efficient priority setting, however, depends upon the availability of accurate data. We found that 16-21% of death certificate diagnoses did not agree with the consensus causes of death. Most strikingly, *unknown* was rarely used as a death certificate cause of death despite 14% of deaths having unknown as a consensus cause of death. As data presented below will show, infants whose cause of death cannot be determined have different characteristics and potentially different causes of death than infants whose cause of death could be determined. Interestingly, we found that death certificate data overestimates the SIDS rate by approximately 20% suggesting that reporting bias has contributed to the high SIDS rates found in Alaska (2).

Because of these issues, persons responsible for the recording of vital statistics data should take all precautions to assure the accuracy of these data. One step towards this goal has been the creation of the Medical Examiner's Office which now obtains medical records for all infant deaths.

The accuracy of death certificate data could also be improved by a stricter use of SIDS as a cause of death. An expert panel convened by the National Institute of Child Health and Human Development has recommended the following definition for SIDS<sup>3</sup>:

The sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.

Cases which do not meet this definition should receive a diagnosis which reflects the likely asphyxial nature of death but which does not suggest SIDS as the etiology. Unfortunately, budget limitations have restricted the ability of the Medical Examiner's office to become involved with issues of public health importance including coordination of death scene investigations with law enforcement officials.

**Based on our findings, the MIMR Committee recommends:**

- Resources should be provided to allow input in infant mortality reviews from all relevant sources.
- Use of SIDS as a cause of death should imply that results of a complete autopsy, death scene examination, and review of clinical history have been considered. Adequate resources should exist to allow the collection and coordination of this information; in particular, increased funding will allow the Medical Examiner's Office to support investigation of pediatric issues.
- Where data is lacking or inconclusive, persons filling out death certificates should use other appropriate terminology, such as "asphyxia of unknown etiology," rather than SIDS.

## Sudden Infant Death Syndrome

### Findings

Examination of 1979-92 death certificate data from the Alaska Bureau of Vital Statistics demonstrated that the SIDS rate during 1979-92 was 2.6 per 1000 live births per year. The overall rate decreased from 2.9 during 1979-85 and 1986-92, respectively. While SIDS rates decreased from 1979-85 to 1986-92 for all gender and racial groups examined, males

and Alaska Natives continue to have higher rates than females and whites (Figure 1).

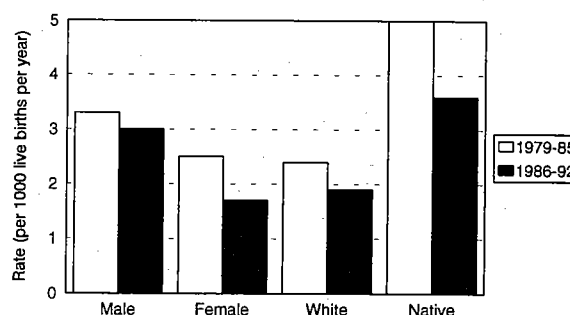
Among the 121 infants deaths which occurred during 1992-94 and were reviewed, the MIMR committee identified 28 cases of SIDS. Factors we analyzed which did not appear to be associated with SIDS included gestation, birthweight, neonatal stress, maternal anemia during pregnancy, method of delivery, maternal age, history of previous fetal loss, vaccination history (including diphtheria, pertussis, tetanus, *Haemophilus influenzae type B*, polio, and hepatitis B), maternal or paternal education, postnatal growth, breastfeeding, and seasonality.

Of 28 children with SIDS, six had an underlying illness at birth including one who was born small for gestational age, one who had an intraventricular hemorrhage, and four who had apnea, bradycardia, or temperature instability at birth. Symptoms consistent with a viral upper respiratory illness occurred within one month before death among 39% of infants with SIDS.

We compared maternal smoking before and during pregnancy among infants who died of SIDS and infants who died of another cause. We found that smoking occurred more frequently at both times among mothers of infants who died of SIDS (Table 2).

We examined the frequency of particular life stressors occurring among the families of

**Figure 1. Sudden infant death syndrome rates, by gender, race, and time period; Alaska, 1979-92**



**Table 2. Comparison of maternal smoking among infants who died of sudden infant death syndrome (SIDS) and infants who died of another cause; Alaska Maternal-Infant Mortality Review, 1992-94.**

	SIDS	Other	Risk ratio (95% CI)
Smoking before pregnancy	15/28 (54%)	27/77 (35%)	1.7 (0.9, 3.3)
Smoking during pregnancy	14/28 (50%)	20/83 (24%)	2.3 (1.2, 4.2)

**Table 3. Time of death risk factors for sudden infant death syndrome; Alaska Maternal-Infant Mortality Review, 1992-94.**

**Highly suggestive**

- Prone position: 83% (19 of 23\*)
- Loose blanket covering: 83% (10 of 12\*)

**Moderately suggestive**

- Placed asleep on a heavy pad or blanket: 31% (4 of 13\*)
- Pillow in bed: 31% (4 of 13\*)

**Less suggestive**

- With a baby-sitter at time of death: 23% (6 of 26\*)
- In bed with another person: 19% (3 of 26 with an adult, 2 of 26 with a sibling\*)

\* Information regarding the death scene was not always available even when the parents agreed to a home interview; consequently, we present the number of interviews upon which the percentage was based.

SIDS victims including divorce or separation, serious illness in the family, death of a relative or friend, arrest or conviction, injury, loss of a job, significant debt, or homelessness. We compared data from MIMR to data collected during 1990-93 from the Pregnancy Risk Assessment Monitoring System (PRAMS, a randomized survey of Alaska mothers who have recently had a live newborn<sup>4</sup>). Overall, 19% of women who had an infant die of SIDS reported none of the above stresses compared to 41% of all women who gave birth; 44% of women whose infant died of SIDS reported three or more of the above stresses compared to 25% of all women who gave birth.

Some sleep related factors had a high prevalence among infants who died of SIDS, particularly prone sleeping position and loose blanket coverings at the time of death (Table 3). Additionally, one-third of children slept with a pillow or on a heavy blanket or pad.

Overall, nine pathologists performed autopsies on infants who died of SIDS. Findings at autopsy included petechiae at one or more locations (86%), pleural petechiae (64%), thymic petechiae (61%), epicardial petechiae (39%), and pulmonary petechiae (14%). Additionally, weight gain was less than 20 g per day for three children; 32% had no bodyweight at autopsy.

### **Recommendations**

We found that the SIDS rate decreased for all demographic groups examined from 1979-85 to 1986-92. Unfortunately, males and Alaska Natives continue to have disproportionately high SIDS rates. Analysis of MIMR data attempted to go beyond demographic data and isolate possible causal factors. One of the great limitations of the MIMR, however, is that no control group exists for comparison. For example, we found that 83% of infants who died of SIDS slept in the prone position; however, we do not know if this is more or less than the rate of prone sleeping among all infants in Alaska. Nevertheless, our data in combination with national studies leads us to some recommendations.

With few contradictions<sup>5</sup>, most studies in the United States and elsewhere have documented that SIDS rates may be decreased by recommending that mothers put their infants to sleep in the supine rather than the prone position<sup>6</sup>. The high rates of prone sleeping among SIDS victims in Alaska suggests a similar education campaign may have success in our state. Similarly, in addition to our findings, a large body of data supports the association between maternal smoking during and after pregnancy and risk of SIDS<sup>7</sup>. This may explain some of the difference between Alaska Native and white SIDS rates: Alaska PRAMS data indicates that 31% of Alaska Natives and 19% of whites report smoking tobacco during the last three months of pregnancy (Alaska PRAMS Project, unpublished data).

A growing body of evidence suggests that a variety of infections, including viral upper respiratory tract illnesses, may predispose infants to SIDS<sup>8</sup>. Additionally, some authors have suggested that SIDS may occur as the result of toxin production from organisms such as *Clostridium perfringens* and *botulinum*<sup>9,10</sup>. The endemic nature of *C. botulinum* in some traditional Alaskan foods makes the latter possibility particularly intriguing in Alaska. Currently, however, no protocol exists for the collection of specimens at autopsy from infants suspected to have died of SIDS.

**Based on our findings, the MIMR committee recommends:**

- **Intensive, well-funded, and sustained education campaigns for pregnant women and new mothers emphasizing preferred sleeping position, appropriate bedding, and the dangers associated with pre and postnatal tobacco cigarette smoking.**
- **Focusing educational campaigns among communities with predominantly Alaska Native residents.**
- **Appropriate funding and staff to allow the Medical Examiner's office to collect routinely blood cultures for bacteria and viral nasopharyngeal cultures of infants who die outside of the hospital. Additional cultures may include bacterial and viral pulmonary cultures and *C. botulinum* or *perfringens* cultures and toxin determination.**
- **Dedication of resources - including staff, equipment, and training - to improve the quality and quantity of data collected during infant autopsies. A standardized minimum level of information should be collected for each infant.**

# Congenital Anomalies

## Findings

Examination of 1979-92 death certificate data from the Alaska Bureau of Vital Statistics demonstrated that the mortality rate from congenital diseases (ICD-9 codes 740-59) during 1979-92 was 1.9 per 1000 live births per year. The overall rate decreased from 2.1 to 1.8 per 1000 live births per year during 1979-85 and 1986-92, respectively. The congenital disease specific mortality rates among males and females during 1979-92 were 2.0 and 1.8 per 1000 live births per year, respectively. The mortality rates among whites and Alaska Natives were 1.8 and 2.5 per 1000 live births per year, respectively. From 1979-85 to 1986-92, the congenital disease specific mortality rate decreased by 39% and 25% among Alaska Natives and males, respectively, and by 11% and 9% among whites and females, respectively.

The most common congenital causes of death during 1979-92 were congenital heart anomalies (0.59/1000 live births/year), trisomy 13, 18, or 21 (0.27/1000 live births/year), anencephaly (0.14/1000 live births/year), anomalies of the urinary system (0.11/1000 live births/year) and anomalies of the diaphragm (0.11/1000 live births/year). Deaths due to anencephaly, anomalies of the diaphragm, and anomalies of the urinary system decreased by 78%, 9%, and 6%, respectively, from 1979-85 to 1986-92 while death due to chromosomal

trisomies and congenital heart disease increased by 37% and 20%, respectively, during the same period.

Because we have not reviewed all deaths which occurred during 1992-94, we cannot produce overall or condition-specific rates for congenital diseases from examination of MIMR data. Of the 121 deaths we have reviewed to date, 13 infants died with chromosomal trisomies including eight with trisomy 13 and three with trisomy 18, seven infants died from a congenital heart defect, and no children died from anencephaly. If these proportions hold for the remainder of the charts, anticipated rates will equal 0.78 per 1000 live births per year for all trisomies combined, 0.48 per 1000 live births for congenital heart disease, and 0 for anencephaly.

## Recommendations

Our data indicate that death due to anencephaly has decreased considerably during 1979-92 and preliminary data from review of MIMR data suggests this trend is continuing. The reason for this decline is unknown but may reflect improved nutrition, particularly intake of folic acid, by pregnant women<sup>11,12</sup>. Additionally, advances in prenatal diagnosis followed by elective abortion may result in fewer liveborn infants with anencephaly.

Deaths due to a chromosomal trisomy, most commonly 13 or 18, have increased dramatically during 1979-92 and preliminary results from review of MIMR data suggests this trend has continued through 1994. We analyzed data provided by the National Center for Health Statistics and found that in the United States as a whole the mortality from trisomies 13 and 18 combined equalled 0.16-0.17 per 1000 live births per year during 1985-90 and had not changed during this time period. This rate was 50-100% lower than the rate for Alaska during 1979-93.

We found that congenital heart anomalies which were lethal during the first year of life increased during 1979-92. Data from other areas suggest that the incidence of all congenital heart anomalies has increased<sup>13</sup>, but the reason for this remains unknown.

### Based on our findings, the MIMR committee recommends

- No extraordinary allocation of funds to decrease mortality from anencephaly at this time.
- Further investigation to determine the explanation for the increase in chromosomal trisomies.

# Unknown Cause of Death

## Findings

Among the 121 deaths which occurred during 1992-4 we identified 17 children for whom we could not determine a cause of death. For five of these children, the death certificate diagnosis was also unknown, for seven the death certificate listed SIDS as the cause of death, and for the remaining five the death certificate listed a variety of diagnoses. For nine of the infants, the review committee felt that abuse or neglect may have contributed to or directly resulted in death, including two with a death certificate diagnosis of SIDS. For four of the infants infection may have contributed to or directly resulted in death, including two with a death certificate diagnosis of SIDS.

Of the 17 infants, 47% were less than the 5th percentile for height or weight or both at the time of death and 47% had a weight gain of 20 g or less per day between birth and death. Compared to infants who died of other causes, infants whose cause of death was unknown were more likely to have no insurance or Medicaid, less than adequate prenatal care, been bottle-fed at some point in their lives, and had a mother who smoked tobacco before pregnancy (Table 4).

Table 4. Comparison of risk factors for infants whose cause of death could not be determined compared to infants with a known cause of death; Alaska MIMR, 1992-94.

Risk factor	Odds ratio of risk factor among unknown deaths compared to other deaths	95% Confidence Limits
Ever bottle-fed	16.0	1.8, 363.2
Less than adequate prenatal care*	3.3	1.0, 11.1
Mother smoked tobacco before pregnancy	3.2	0.9, 12.1
No insurance or Medicaid	2.7	0.7, 10.8

\*As defined by the Kessner index<sup>14</sup>

Eighty-eight percent of infants who died from an unknown cause had an autopsy. The most common finding was pleural, pulmonary, epicardial, or thymic petechiae, found in 73% of infants.

## Recommendations

We found that, despite performance of autopsies in most instances, a cause of death could not be determined for 14% of all infants. A review of the medical records and the characteristics of

deaths of unknown cause suggest the possibility that some of the deaths resulted from abuse or neglect. In particular almost half of these infants had evidence of failure to thrive and poor growth, a finding often associated with neglect in the absence of organic etiologies. Additionally, while bottle feeding may occur for a variety of reasons, the very high prevalence of bottle feeding in this population may reflect less interest in the infant by the mother.

Recent literature has suggested the possibility that some deaths labeled SIDS actually result from abuse or neglect<sup>15,16</sup>. Studies of infants at autopsy have attempted to define differences between infants with SIDS and infants dying from homicide. However, while some types of petechiae may be more common among SIDS victims than victims of intentional suffocation, the required specificity for making this determination does not exist<sup>17</sup>.

The MIMR committee noted that pathologists may use SIDS as a diagnosis at autopsy - even when inadequate information exists to determine this cause of death - so that the family may obtain bereavement services through SIDS support groups. Unfortunately, support groups for families who have lost an infant who died of a cause other than SIDS may not be available.



Based on our findings, the MIMR committee recommends:

- Through training, law enforcement officers, clinicians, coroners, and pathologists should remain vigilant for the possibility of abuse or neglect for all sudden, unexplained infant deaths.
- Appropriate information should be collected to help differentiate death due to abuse and neglect from death due to other causes.
- Law enforcement officers should receive training on conducting a death scene investigation for an infant death and should collect routine, standardized information. They should provide this information to the coroners, the Medical Examiner's Office and to the Alaska MIMR.
- Bereavement services should be available statewide for all families who have lost an infant, not just those whose infants died of SIDS.

*Submitted by: Bradford D. Gessner, M.D. for the Alaska Maternal-Infant Mortality Review Committee.*

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